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# Report title

Date of report

**END OF LIFE CARE**

**Summary of work undertaken by Dementia United 2020 to 2022**

Version 1.0

May 2023

## Author

xxxx

Report to

Title of meeting

### Exec Summary

Xxxxxx

### Content table if long report

Xxxxxx

### Background

Xxxxxx

### Content

Xxxxxx

### Conclusion & Recommendations

Xxxxxx



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This report summarises the work undertaken in partnership with the Strategic Clinical network during 2020/2022.

During this time, we worked with the Strategic Clinical Network Palliative and End of Life Care Team to progress work in relation to the End of Life Care. It was agreed that Dementia United would partially fund this work with the SCN taking the lead in project delivery; but Dementia United remaining involved as stakeholders.

This work has now been completed by the SCN as summarised below, and in 2023 Dementia United resumed the lead role for this area of project delivery.

# About the project

Dementia and Alzheimer’s disease have been the leading cause of death in England since 2015 (Office of National Statistics). However, dementia is still not universally recognised as life-limiting and when people are in the dying phase, they are often no longer in contact with dementia specialists (58% of people with dementia will die in the care home setting). It can be difficult to predict disease progression and to identify the dying phase. Advanced dementia is also associated with increased symptom burden but due to the inability to communicate, this can be interpreted as general agitation which is often not properly investigated. Consequently, people with dementia may receive sub optimum end of life care, including inadequate pain management.

Our aim was to develop a bespoke dementia end of life training package for primary care networks and care home teams, utilising the University College London’s rules of thumb guide. This guide was created as part of a research project funded by Marie Curie and Alzheimer’s Society and was developed by an experienced team of researchers and health and social care professionals, including GPs and psychiatrists and a group of family carers. The training content is designed to be consistent across Greater Manchester whilst allowing for flexibility in delivery to suit locality needs. The project took a pump-prime approach with interested locality educators delivering a small number of sessions in their locality. Primary care networks and care homes were selected as 58% of people with dementia will die in the care home setting. The training also supported the [Enhanced Health in Care Homes Framework](https://www.england.nhs.uk/publication/enhanced-health-in-care-homes-framework/).

Dying with dementia brings unique challenges that can be difficult to manage without training. We hoped that, by delivering the training to primary care network and care home teams who work together to support 58% of people dying with dementia, a shared language and consistent tool would help them feel more confident in meeting the unique needs of those dying with dementia and their carers.

# What we achieved

* Agreed on a [Greater Manchester syllabus for dementia end of life training](https://dementia-united.org.uk/wp-content/uploads/sites/4/2020/10/GM-End-of-Life-Dementia-training-Syllabus-v0.5.pdf) with a big focus on the [University College London’s rules of thumb guide](https://dementia-united.org.uk/wp-content/uploads/sites/4/2021/01/03-UCL-Rules-of-Thumb-Guide-v14.0_PRINT-version.pdf)
* Greater Manchester hospice educators translated the syllabus into a lesson plan and slides designed to be delivered to primary care network and care home teams
* Training webinar tested with a Trafford team and adjustments made accordingly
* Educator Packs created to help interested educators plan, deliver content and evaluate training consistently across Greater Manchester (although flexibility will be allowed in delivery according to educator’s locality needs, content will remain constant).

# End of Life Care Resources

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For details about our latest work on End Of Life please contact: Karen Thakuria or visit our website <https://dementia-united.org.uk/>